266 'Arresting' psychological issues for better health outcomes in parents of infants and young children with cystic fibrosis

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Background: Children enrolled in the AREST CF early surveillance program undergo annual CT scan thorax and bronchoscopy under general anaesthetic to detect signs of early lung disease. How well caregivers cope with the annual procedures and with knowledge of their child's covert disease progression is unknown.
Objectives: To report the range of caregiver coping behaviours and maladaptive coping that may benefit from psychosocial intervention.
Methods: A qualitative research design using semi-structured interviews for caregivers of children with CF recruited from Perth and Melbourne CF Clinics. Items explored coping strategies and effectiveness related to the annual surveillance program. Thematic analysis identified a range of coping strategies.
Results: 49 caregivers (11 fathers, 38 mothers) of children aged 1–6 years (m = 3 years) participated. Coping with annual surveillance procedures is predominantly emotion-focussed, whilst coping with the knowledge of covert disease progression is problem-focussed. The primary maladaptive copying strategy was cognitive avoidance. Overall, coping among caregivers was adaptive with many drawing positive value from negative events. The perceived benefits of early detection and treatment of lung disease enables parents to cope with the knowledge of covert disease progression.
Conclusions: Caregiver coping influences the emotional wellbeing of young children. Screening for coping styles could identify caregivers and children who may benefit from targeted psychosocial family support and surveillance.

267 Bringing bad news: the diagnosis of cystic fibrosis in childhood

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Objectives: The day parents are told their child has Cystic Fibrosis (CF) is imprinted in their memory. Parents often show strong emotions (e.g. shock, anxiety) and they need to restructure their lives taking into account CF (Jedlicka-Köhler, Götz & Eichler, 1996; Monestrol et al, 2011).
Methods: Following a pilot study the aim of this study is (1) to explore how parents (n = 38) of 20 children with CF (diagnosed during the past 5 years) recall hearing the CF diagnosis and the information they received and (2) to explore their current ways of coping (Utrecht Coping List, Schreurs et al, 1988).
Results: No differences between fathers and mothers were found. All parents were informed by the CF specialist, but 20/38 parents first heard the term 'CF' from their local pediatrician. All parents recalled specific details about the information they were given, their thoughts and emotional reactions. Parents were satisfied with the information and the way it was provided. Parents (21/38) remembered the doctor showed personal emotions. The other parents felt comfortable with the doctor not showing personal emotions. Coping results showed that 22/38 parents showed an adaptive primary control coping style, 10 reported a passive coping style, which is less adaptive. The latter was associated with recall of negative feelings and thoughts at the time of diagnosis.
Conclusion: The interviews evoked strong memories. All parents were pleased with the information provided at the time of diagnosis. All recalled details, both practical and emotional. Occasionally in clinic it is important to consider parents' memory of the period of diagnosis, as this may shed light on their coping styles.

268 The experiences of young people and their parents in the move from paediatric to adult cystic fibrosis services in Bristol: recommendations for an improved transition pathway

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Objectives: Transition to adult healthcare services requires careful planning and preparation. The paediatric and adult CF services in Bristol aim to improve transition experiences, to ensure patients and families are adequately prepared and ultimately reduce risk of health deterioration in young adulthood.
Methods: This qualitative study explored the experiences of young people with CF and parents in the transition from Bristol Royal Children's Hospital to the adult service at the Bristol Royal Infirmary. Semi-structured interviews with five young people and three parents took place and were thematically analysed.
Results: A key theme to emerge was the perception of suddenly leaving the familiar, secure "family" of the paediatric team, who many had known since birth. Denial, anger and anxiety were all evident. Patients had to build new relationships with the adult team, starting at a very different time in life, making decisions and choices as adults in charge of their own health. Transition was viewed as the discrete transfer point rather than a process. Parents took a step back, a change that some found challenging.
Conclusion: Rich data emerged highlighting the complexities of transition and the need to support both patients and parents. Themes are discussed along with service recommendations including a transition focused parents evening hosted by the adult team. Traditionally provided by paediatric services, it is hoped that this approach will help manage the development of new relationships which is crucial for successful transition. A further area for investigation is the experience of families transferring to the central adult service from smaller regional teams.

269 When I am grown up − evaluating the effectiveness of a transition program for adolescents with CF transferring to the adult hospital system

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Objectives: An adolescent transition program has run for Cystic Fibrosis (CF) patients for one year at the Royal Children's Hospital (RCH) Melbourne. Effective transition improves patient health and life outcomes, and improves self-care. Evaluation is needed to ensure the program addresses the population's needs.
Methods: 51 adolescents with CF were invited to participate in the one year pilot transition program. 14 15–17 year olds completed and returned pre-questionnaires describing their experience in clinic, self-management of their disease and preparedness for adult hospital. This was repeated at the end of the study.
Results: 14 patients returned pre-questionnaire; 5 returned post-questionnaires. Results indicated improvements in visits to doctor alone (0% pre, 40% post); booking appointments (22 vs. 60%); and taking medication without reminders (46 vs. 100%). Improvements were also seen in discussions of emotional well-being (38 vs. 80% post); risk factors (61% vs. 100%); and confidentiality (40 vs. 80%). Large improvements were found in the adolescent's preparedness for adult hospital (45 vs. 100%). Post-transition, 80% of participants reported that they had learnt something; 60% had taken more responsibility for their illness; and 80% felt more confident about navigating the healthcare system.
Conclusion: The results of this small pilot study indicated a general improvement in patient responsibility, confidence and preparedness for transition. It suggests that the transition program is a useful and valued program that is supporting adolescents and their families to take on increasingly more responsibility for their own health.